

104TH CONGRESS  
1ST SESSION

# S. 1416

To establish limitation with respect to the disclosure and use of genetic information, and for other purposes.

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## IN THE SENATE OF THE UNITED STATES

NOVEMBER 15, 1995

Mr. HATFIELD (for himself and Mr. MACK) introduced the following bill; which was read twice and referred to the Committee on Labor and Human Resources

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## A BILL

To establish limitation with respect to the disclosure and use of genetic information, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Genetic Privacy and  
5 Nondiscrimination Act of 1995”.

6 **SEC. 2. FINDINGS AND PURPOSES.**

7 (a) FINDINGS.—Congress finds the following:

8 (1) The DNA molecule contains information  
9 about an individual’s probable medical future.

1           (2) Genetic information is uniquely private and  
2           personal information that should not be disclosed  
3           without the authorization of the individual.

4           (3) The improper disclosure of genetic informa-  
5           tion can lead to significant harm to the individual,  
6           including stigmatization and discrimination in areas  
7           such as employment, education, health care and in-  
8           surance.

9           (4) An analysis of an individual's DNA provides  
10          information not only about an individual, but also  
11          about the individual's parents, siblings and children.

12          (5) Current legal protections for genetic infor-  
13          mation, tissue samples and DNA samples are inad-  
14          equate to protect genetic privacy, and require fur-  
15          ther attention.

16          (6) Laws for the collection, storage and use of  
17          identifiable DNA samples and private genetic infor-  
18          mation obtained from those samples are needed both  
19          to protect individual privacy and to permit legitimate  
20          genetic research.

21          (b) PURPOSES.—It is the purpose of this Act to—

22                (1) define the rights of individuals whose ge-  
23                netic information is disclosed;

24                (2) define the circumstances under which an in-  
25                dividual's genetic information may be disclosed; and

1           (3) protect against discrimination by an insurer  
2           or employer based upon an individual's genetic infor-  
3           mation.

4 **SEC. 3. DEFINITIONS.**

5           As used in this Act:

6           (1) DNA.—The term “DNA” means  
7           deoxyribonucleic acid.

8           (2) DNA SAMPLE.—The term “DNA sample”  
9           means any human biological specimen from which  
10          DNA can be extracted, or the DNA extracted from  
11          such specimen.

12          (3) EMPLOYER.—The term “employer” has the  
13          same meaning given such term in section 3(d) of the  
14          Fair Labor Standards Act of 1938 (29 U.S.C.  
15          203(d)).

16          (4) GENETIC INFORMATION.—The term “ge-  
17          netic information” means the information about  
18          genes, gene products or inherited characteristics that  
19          may derive from an individual or a family member.

20          (5) GENETIC TEST.—The term “genetic test”  
21          means a test for determining the presence or ab-  
22          sence of genetic characteristics in an individual, in-  
23          cluding tests of nucleic acids such as DNA, RNA  
24          and mitochondrial DNA, chromosomes or proteins in  
25          order to diagnose a genetic characteristic.

1           (6) INSURER.—The term “insurer” means an  
2           insurance company, health care service contractor,  
3           fraternal benefit organization, insurance agent, third  
4           party administrator, insurance support organization  
5           or other person subject to regulation under State in-  
6           surance laws. Such term includes self-funded health  
7           plans and health plans regulated under the Em-  
8           ployee Retirement Income Security Act of 1974 (29  
9           U.S.C. 1001 et seq.).

10           (7) SECRETARY.—The term “Secretary” means  
11           the Secretary of Health and Human Services.

12   **SEC. 4. REQUIREMENTS FOR DISCLOSURE OF GENETIC IN-**  
13           **FORMATION.**

14           (a) PROHIBITION.—

15           (1) IN GENERAL.—Except as provided in para-  
16           graph (2), regardless of the manner in which genetic  
17           information was received, or of the source of such  
18           information, including information received from an  
19           individual, an entity may not disclose or be com-  
20           pelled (by subpoena or any other means) to disclose  
21           genetic information about an individual unless such  
22           disclosure is specifically authorized by the individual  
23           involved or the legal representative of the individual  
24           through a written authorization which includes a de-  
25           scription of the information being disclosed, the

1 name of the individual or entity to whom the disclo-  
2 sure is being made, and the purpose of the disclo-  
3 sure.

4 (2) EXCEPTIONS.—Notwithstanding paragraph  
5 (1), genetic information concerning an individual  
6 may be disclosed if such disclosure—

7 (A) is authorized under Federal or State  
8 criminal laws relating to the identification of in-  
9 dividuals, or as is necessary for the purpose of  
10 a criminal or death investigation, a criminal or  
11 juvenile proceeding, an inquest, or a child fatal-  
12 ity review by a multidisciplinary child abuse  
13 team;

14 (B) is required under the specific order of  
15 a Federal or State court;

16 (C) is authorized under Federal or State  
17 law for the purpose of establishing paternity;

18 (D) is for the purpose of furnishing genetic  
19 information relating to a decedent to the blood  
20 relatives of the decedent for the purpose of  
21 medical diagnosis; or

22 (E) is for the purpose of identifying bodies.

23 (b) APPLICATION OF SECTION.—The prohibitions of  
24 this section shall apply to any redisclosure by any entity  
25 after another entity has disclosed the genetic information.

1 **SEC. 5. PROHIBITION ON CERTAIN EMPLOYMENT PRAC-**  
2 **TICES.**

3 (a) DISCRIMINATION AS TO RIGHTS OR BENEFITS.—  
4 No employer may seek to obtain, obtain, or use the genetic  
5 information of an employee or a prospective employee, or  
6 require a genetic test of an employee or prospective em-  
7 ployee, to distinguish between or discriminate against or  
8 restrict any right or benefit otherwise due or available to  
9 the employee or prospective employee.

10 (b) ENFORCEMENT.—The powers, remedies, and pro-  
11 cedures set forth in sections 705 through 709 of the Civil  
12 Rights Act of 1964 shall be the powers, remedies, and pro-  
13 cedures this section provides to any person alleging a vio-  
14 lation of this section.

15 **SEC. 6. REQUIREMENTS RELATING TO INSURERS.**

16 (a) GENERAL PROHIBITION.—An insurer offering  
17 health insurance may not use genetic information to re-  
18 ject, deny, limit, cancel, refuse to renew, increase the rates  
19 of, or otherwise affect health insurance.

20 (b) PROHIBITION ON INDUCEMENT.—With respect to  
21 a genetic test conducted in accordance with subsection (c),  
22 an insurer may not use such a genetic test as an induce-  
23 ment for the purchase of insurance.

24 (c) PERMISSIBILITY OF TESTS.—If an insurer re-  
25 quests that an applicant for insurance (other than an ap-  
26 plicant for health insurance) take a genetic test in connec-

1 tion with an application for insurance, the use of the re-  
 2 sults of such test shall be disclosed to the applicant and  
 3 the insurer shall obtain the specific written authorization  
 4 of the applicant for such disclosure.

5 (d) APPLICATION.—This section shall apply only to  
 6 insurance policies issued on or after the date of enactment  
 7 of this Act, and to the renewal of policies issued before,  
 8 on, or after such date of enactment.

9 **SEC. 7. FURTHER RECOMMENDATION BY THE NATIONAL**  
 10 **BIOETHICS ADVISORY COMMISSION.**

11 Not later than August 31, 1996, the National  
 12 Bioethics Advisory Commission shall prepare and submit  
 13 to the appropriate committees of Congress a report con-  
 14 taining recommendations on—

15 (1) the development and implementation of  
 16 standards to provide increased protection for the col-  
 17 lection, storage, and use of identifiable DNA sam-  
 18 ples and genetic information obtained from those  
 19 samples; and

20 (2) the development and implementation of ap-  
 21 propriate standards for the acquisition and retention  
 22 of genetic information in all settings, including ap-  
 23 propriate exceptions.

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